Health Sector Transition and Recovery Programme

Final Report to MoH's Disability and Rehabilitation Focal Unit (DRFU)

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स्पाइनल इन्जरी पुनर्स्थापना केन्द्र
Spinal Injury Rehabilitation Centre
A Project of Spinal Injury Sangh Nepal

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Handover Report of Work by SIRC to MoH's Disability and Rehabilitation Focal Unit (DRFU)

Executive Summary

This report offers a single service provider's perspectives and insights into selected inputs and outputs of the DFID funded Health Sector Transition and Recovery Programme (HSTRP) established by Nepal's Ministry of Health (MoH) in the aftermath of the major earthquakes of April and May 2015.

Under HSTRP, SIRC was contracted to implement activities designed to address the health and rehabilitation service delivery needs of individuals suffering from spinal cord injuries (SCIs), their families and health professionals working in this area of disability in six earthquake affected districts (Sindhupalchowk, Nuwakot, Rasuwa, Kavre, Dolkha and Ramechhap).

The purpose of this report is to present:

- learning drawn from the collective activities of the programme
- a summative account of programme achievements
- knowledge and learning for health sector policy and strategy development on the healthcare and rehabilitative needs of people with disabilities (PWD) in Nepal
- recommendations on how programme learning can inform and influence health system strengthening for SCI rehabilitation services for other post-disaster settings.

Key Findings

Key outputs include comprehensive information on patients' rehabilitation at SIRC which shows significant clinical improvements in their physical and psychological wellbeing. Unusually for a post-disaster programme, several health systems development successes have also been achieved. The programme is judged to represent good value for money in so far as it has helped to satisfy unmet SCI service delivery needs, including for rehabilitation and psychosocial care, in earthquake affected districts in a cost effective manner.

Recommendations

Considering the situation and needs of those with disabilities in post-earthquake settings, there is a clear need for strong coordination and collaboration mechanisms between ministries, national and international organizations, service providers and others providing financial and technical support if needs are to be identified, services provided and patients' lives improved. In addition, in order to reach those residing in areas lacking health services, public private partnerships between the Government and private sector organizations, including NGOs, are put forward as a viable option.

Section 12 provides a more detailed description of programme recommendations presented against the six categories that make up WHO's health systems strengthening framework, namely 1) Leadership and Governance; 2) Service Delivery; 3) Human Resources; 4) Information Systems; 5) Health Technologies and 6) Health Financing.

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LIST OF ACRONYMS

ASCoN	Asian Spinal Cord Network
CBR	Community Based Rehabilitation
DASS	Depression Anxiety Stress Score
DFID	Department for International Development
DRFU	Disability and Rehabilitation Focal Unit
FP	Focal Point
GoN	Government of Nepal
HI	Handicap International
IRSC	Injury and Rehabilitation Sub-cluster
ISCoS	International Spinal Cord Society
M&E	Monitoring and Evaluation
MDT	Multi-Disciplinary Team
MoH	Ministry of Health
NGO	Non-government Organization
NHSP	Third Nepal Health Sector Programme
NHSS	National Health Service Strategy
NPAPD	National Policy and Action Plan on Disability
PDNA	Post Disaster Needs Assessment Framework
PWD	People with Disabilities
SCI	Spinal Cord Injury
SCIM	Spinal Cord Independence Measure
SIRC	Spinal Injury Rehabilitation Centre
ToC	Theory of Change
TPO	Transcultural Psychosocial Organization
WHO	World Health Organization

1. INTRODUCTION

A fiscal commitment of ten million British pounds was made by the UK Government as a part its response to Nepal's earthquakes of April and May 2015. DFID recognized that "the provision of health services and rehabilitation to those families most affected (by physical and mental trauma) will enable them to rebuild their livelihoods and will allow affected districts to return to productivity".

Specifically DFID projected that under the HSTRP "18,000 people injured in the crisis will gain access to rehabilitation care, physiotherapy and psycho-social support." Figure 1 shows the "Theory of Change" used by DFID to map out its investment and the returns predicted as a result of activities undertaken during the 14 month programme period to September 2016.

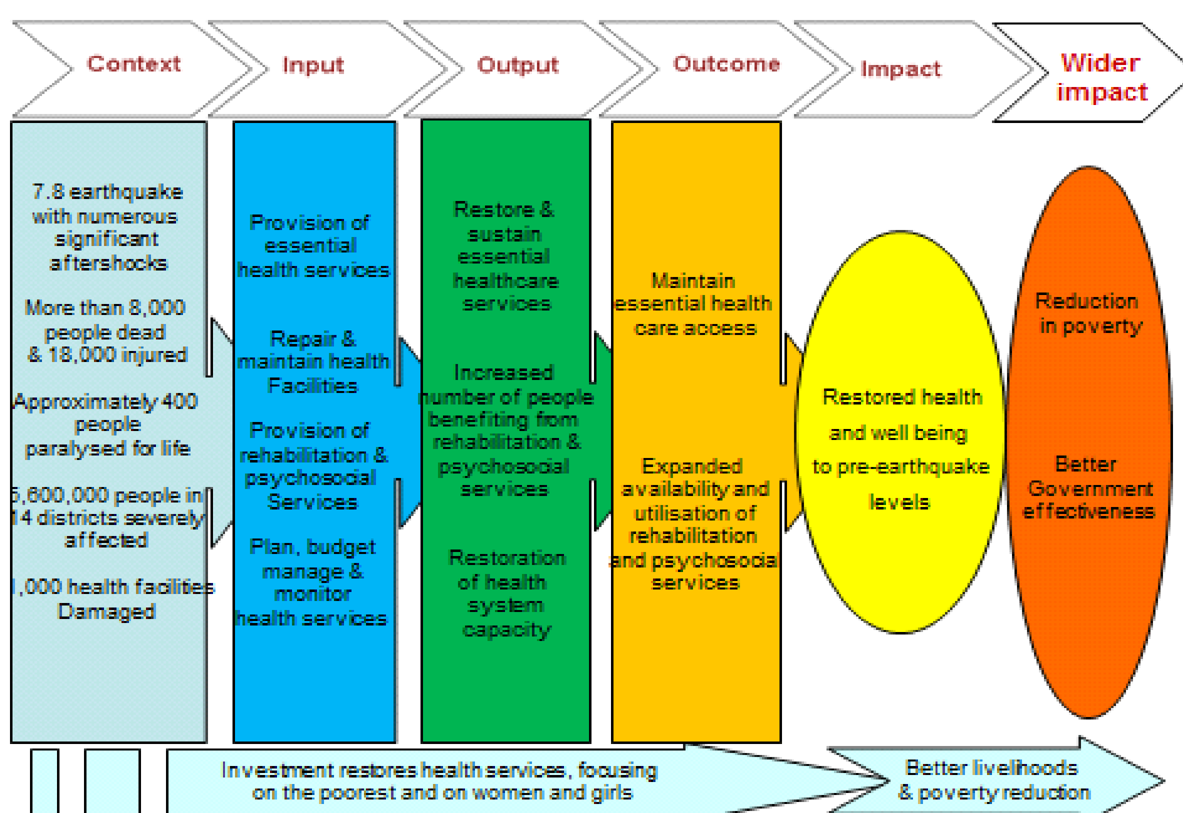

Figure 1: DFID Theory of Change

The purpose of this report is to present learning from across the SIRC programme. The application of a comprehensive monitoring and evaluation (M&E) framework at each stage ensured that both process and outcome information was gathered for each objective and the associated activities. The resulting summative account of programme achievements was enhanced through a reflective examination of evidence and processes in order to identify "what was the learning?" and how this might inform and influence future activities in SCI rehabilitation. The learning highlighted in this report also takes into account several value for money (VFM) assessment categories (Table 1) used by DFID when preparing its business case.

Table 1: DFID Value for Money Assessment Criteria

What to assess?	How to assess?
Economy	Average national, regional, and international expertise rates Percentage of days/ expenditure by national consultants Ratio of national to international technical assistance
Efficiency	Administration and management as a percentage of the total expenditure Unit cost per training participant
Effectiveness	Government approval rate of technical assistance products Technical assistance products that are supply led versus demand driven Technical assistance products that are strategic versus short-term
Cost Effectiveness	Case studies of technical assistance products to quantify impacts

2. LESSONS LEARNED FROM THE DFID ANNUAL REVIEW, 2016

During the HSTRP annual review carried of July 2016, it was reported that, “overall this programme is delivering effective and much needed interventions”. Specifically, “DFID’s approach of combining earmarked financial aid with technical assistance (TA) has contributed to the restoration of health services across many key indicators in the 14 most earthquake (EQ) affected districts”.

This quote was supported by data that showed “the utilization of key services is higher than the average for the 31 EQ affected districts and the national average”. Reference was also made to unexpected outcomes in the form of system level changes: “Unusually for a post-disaster programme, the programme is achieving systems as well as service delivery level outcomes. The programme presents good value for money, particularly as it focuses on access to essential health care services and on areas of unmet need for spinal injury, rehabilitation and psychosocial care in a post-disaster context”. The main lessons identified in the annual review pointed to:

- DFID Nepal’s existing programme and relations with the Government of Nepal (GoN), Ministry of Health (MoH) and external partners significantly enabled the rapid development and implementation of this programme;
- The ability to impact systems resulted in a more rapid implementation and greater programme efficiency and effectiveness with reduced financial risks than might otherwise have been the case in an activities only approach;
- Strong programme and partner coordination and management and a flexible, adaptable working approach enabled effective implementation, enhanced partnerships and mitigated risks, most notably those related to border restrictions with India including fuel and transportation crises;

- In the context of post-earthquake recovery where specific needs emerge during implementation, a more flexible approach to output-based contracts is needed, allowing the modification of deliverables to reflect on-the-ground and rapidly changing realities.

3. RESULTS MONITORING

DFID's programme log frame provided the primary tool for "regular monitoring of the overall programme (financial aid and technical assistance) including formal monitoring for annual review purposes". The advantage of using a log frame is that it mirrors the anticipated theory of change (ToC) for the programme and allows for regular reconsideration of theory of change assumptions. In addition, DFID was able to monitor individual service provider deliverables against agreed milestones. The "Achievement of deliverables against regular milestones was a key feature in monitoring service provider performance". These deliverables were directly linked to the contractual agreements between SIRC and DFID managed by Options Consultancy Ltd. Table 2 sets out the programme activities carried out under the programme. These deliverables provided the basis for eliciting the lessons learned which are presented in this report.

Table 2: SIRC Programme Deliverables

S.No. [1]	Deliverables
1	Work plan finalised and approved
2	Carer training programme reviewed and patient self-care manual updated and reprinted
3	Individual needs assessment carried out for each person admitted to SIRC
4	Quarterly progress report 1
5	National And District Level Trainings provided to health and rehabilitation professionals in coordination with Handicap International (HI)
6	Quarterly progress report 2
7	Caretakers programme for 100 caretakers
8	200 ex patients of SIRC living in affected districts have received follow up home visit services support
9	Quarterly progress report 3
10	Referral system established between community and HI district rehabilitation points
11	30 female patients have received vocational training and package upon completion
12	130 people will have received in patient services at SIRC with assessment of functional improvement, psychological acceptance, and management of complications
13	200 ex patients of SIRC living in affected districts have received follow up home visit services and support
14	Hand over report of work by SIRC to the MoH Disability and Rehabilitation Focal Unit (DRFU)
Value Added Outputs [2]	
1	Hands on training to 60 health workers
2	Neuro rehab training to 50 nurses
3	Peer group training in six focal districts
4	Awareness Camp

[1] This numbering does not reflect payment deliverable numbering since it includes contributions to Options deliverables, notably quarterly reports

[2] These reports are available from NHSSP as required

5	Disaster Drill
6	Team Building
7	Programme Management training
8	Institutional follow up of 100 ex-patients

4. METHODOLOGY

A bespoke M&E framework led to the development of a customized database where information related to each activity was coded and stored. A reliable and consistent protocol for data management was applied throughout and across all events/actions. In this way, analytic descriptions could be generated to inform ongoing clinical, operational, and strategic decision making of the programme. Where possible, pre- and post- analyses of indicator data were conducted with tools distributed to patients or participants. Individual reports that include analysis by activity are provided in the Appendices.

4.1 Methods

Applying a mixed methods design, tools including standardized clinical outcome measures such as the Spinal Cord Independence Measure (SCIM) and Depression Anxiety Stress Score (DASS) were used to examine changes in patient wellbeing following rehabilitation at SIRC. This was accompanied by different customised measures tailored to specific training programmes administered at the start and end of events. Feedback forms and surveys were used throughout the programme with focus groups and interviews took place with groups and individuals as appropriate.

4.2 Sample

Table 3 details the number of beneficiaries and stakeholders who participated in each programme activity. This comprised patients, community members, professionals and policy makers. In total, more than 3646 people engaged in the programme period. The divergent profiles of participants highlight the layered and comprehensive structure within which activities and deliverables were intentionally constructed.

Table 3: Participant sample

Activity Details	Participant Type	Number
Work plan finalised and approved	SIRC	Not applicable
Carer training programme reviewed and patient self-care manual updated and reprinted	SIRC	Not applicable
Individual needs assessment carried out for each person admitted to SIRC	Patients admitted to SIRC	145
National and district level trainings provided to health and rehabilitation professionals in coordination with HI	Health and rehabilitation professionals	Approx. 100
Caretakers' programme for 100 caretakers	Caretakers	107
200 ex patients of SIRC living in affected districts have received follow up home visit services and support	Patients of SIRC	217
Referral system established between the community and HI district rehabilitation points	Referred patients of like-minded organisations	97
30 patients have received vocational training and package upon completion	Patients of SIRC	30

130 people will have received in patient services at SIRC with assessment of functional improvement, psychological acceptance, and management of complications	Patients of SIRC	132
200 ex patients of SIRC living in affected districts have received follow up home visit services support	Ex-patients of SIRC	187
Hand over report of work by SIRC to the MoH, DRFU	-	-
Hands on training given to 60 health workers	Health workers	148
Neuro rehab training to 50 nurses	Nurses	50
Peer group training in six focal districts	People with disabilities	129
Awareness Camp	General Public	Approx. 2000
Disaster Drill	SIRC staff	100
Team Building Training	SIRC staff	80
Programme Management Training	SIRC staff	19
Institutional Follow up of 100 patients	10	105
Total participants across all activities		3646*

**This is an approximate figure for the total number of participants across all activities.*

4.3 Analysis

Reflective reviews of outputs and outcomes were a continuous feature in the operational and strategic management of the programme. This approach emerged from a continuous cycle of learning meetings formally organized at SIRC and through existing management protocols such as weekly multi-disciplinary meetings or practitioner level planning meetings. As a result, staff were able to work within the parameters of the M&E framework which was devised to be participatory and reflexive. By adapting the recommendations of the M&E consultant staff served as active change agents who embedded evidence based learning to make data driven decisions. This document summarizes the key findings and highlights the variables that facilitated or impeded the delivery of outputs to improve outcomes at patient, family, community and sector levels.

Individual reports linked to each programme deliverable were subject to appropriate analytic examination dependent on the mode and type of information gathered from participants. This ranged from bivariate repeated design calculations to descriptive accounts following a thematic analysis of qualitative experiences offered by beneficiaries or stakeholders. Each of the individual reports submitted to DFID clearly demonstrated application of this analytic approach appropriate to the data collected across the various deliverables.

Construction of the M&E framework led to a key outcome, namely the provision of comprehensive clinical, spatial, demographic and statistical data on programme deliverables. As a result, SIRC can now confidently contribute to sector level policy and strategy development to better reflect the needs of PWD in Nepal based on robust evidence and learning.

4.4 Findings

The construction of programme objectives and deliverables was mapped to projected benefits for patients, staff, communities and overall strategy development. Table 4 details the proposed intentional outcomes of each activity with an aggregated summary which provided the basis for

related lesson learning. Inspection of benefits points to a series of overlapping indicators that lead patients, staff and policy in the direction of positive change. These combine clinical care with knowledge, awareness, skills and confidence of patients and staff. They direct deliverable actions to achieve projected impacts using a range of human, material, technological and strategic resources. As such, observed changes recorded for each programme objective contribute to an evidence based roadmap to strengthen the health system at SIRC and the development of a stronger health system at national level.

Table 4: Summary of key benefits for DFID funded activities

Activities	Benefits (linked to indicators)
1. Patients - Centre based	
1. Needs assessments of 145 patients	Customized care and treatment provided, fulfilment of patient needs
2. 105 institutional follow ups	Patient care and treatment Patient education Proper hygiene Improvement in quality of life Supported SIRC to design and establish this new service for the admission/readmission of people with SCI living in the community
3. 132 patients - rehabilitation and readmission	Patient care and rehabilitation Patient education Proper hygiene Improved systems of care and updated clinical standards
4. Vocational training package given to 30 patients	Improved knowledge, confidence, and skills concerning patient care Increased capacity to generate income New vocational skills and improved confidence
5. 42 referred patients from the Community Based Rehabilitation (CBR) team	Right treatment at the right time at the appropriate place
6. 404 home based visits and assessments	Short term needs fulfilled, referrals where possible, and data on long term needs assessment
7. 80 telephonic follow ups to ex patients	Needs assessment of patients, follow up visits and readmission of patients at SIRC New system developed at SIRC for this activity
2. Training	
8. Hands on training to 148 district health staff	Trained district level staff on SCI Initial treatment of SCI patients at local level
9. Neuro rehabilitation training to 50 nurses	Trained nurses on Neuro rehabilitation
10. Peer group training in six focal districts	Enriched knowledge on preventing complications related to bowel, bladder, and skin care

	Improved networking and communication with other people with disabilities from the same community Enhanced knowledge on disability rights and facilities that comes along with disability cards
11. Awareness Camp	Increased awareness on SCI, causes, prevention, need for rehabilitation, and information about SIRC
12. Disaster Drill	Trained staff to handle the in/out patients during emergency or critical situation in the future
13. Team Building Training	Increased motivation, great team work, team spirit, and efficient coordination and communication.
14. Programme Management Training	Enhanced knowledge on programme cycle management and M&E
3. Support from National and International Expertise	
15. Support from Consultants	Strengthened internal systems and procedures in relation to: M&E and Lessons Learned Framework Nursing and clinical care provision
16. Livability Support	Well-designed programme with focus on service delivery in the short term and long term system development Effective and efficient M&E framework and standard operating processes Identification and implementation of lessons learned Advisory support and mentorship to strengthen management and leadership of multi-disciplinary team

5. PROGRAMME OUTCOMES

By applying an operationally effective, robust, reliable and clinically sound measurement system, staff at SIRC worked to implement best practices and positively impact patient outcomes. Using a multi-drug therapy (MDT) approach to rehabilitation and using data as a driver of change, SIRC staff across all departments, developed care pathways that were informed and revised based on ongoing monitoring data and assessments of patient functioning.

The comprehensive information on patients' rehabilitation clearly points to statistical clinical improvements in their physical and psychological wellbeing. This has been evidenced through comparisons between assessments at admission and repeated assessments at discharge. The "distance travelled" has been directly calculated using standardized measures such as the Smart Common Input Method (SCIM) and Digital Access Signaling System (DASS). The activities of MDT through professional and practitioner inputs in direct response to measured functioning, informed the delivery of treatments, services and care pathways for patients.

5.1 In patient Activities

Through the MDT approach adapted by SIRC, a thorough assessment of needs was conducted which informed individual patient care plans. This involved taking account of the physical, social,

psychological and vocational needs of patients and responding appropriately to maintain their rehabilitation outcomes. The low level of complications observed among the cohort of 237 in-patients (132 rehabilitation plus 105 institutional follow up) suggests that their rehabilitation experiences at SIRC had prepared them adequately for life with an SCI in their communities through a structured and consistent education programme covering both patients and caretakers. Key messages on SCI management and prevention were embedded in a structured programme of demonstrated techniques of bowel, bladder and pain management, alongside evidence-informed actions to promote functionality and independent day to day living.

There is enough evidence that the programme activities and targets contributed significantly to the improved health and rehabilitation outcomes of patients. Telephonic follow up of patients and CBR home visits proved instrumental in performing needs assessments of patients and assisting them in institutional follow up and re-admission programmes. Physical and psychological gains in the short term can enhance each person's chance of longer term social and economic inclusion and social reintegration post-discharge.

The programme allowed SIRC to systematically review its clinical systems and procedures and the clinical standards and protocols underpinning them. It also supported the rapid development of documentation systems. The cumulative impact of these developments is that many more patients in the future will have a better rehabilitation experience at SIRC. Further, SIRC is now in a stronger position to articulate and demonstrate to policy makers the impacts resulting from the delivery of a comprehensive rehabilitation programme and how this can lead into socio-economic reintegration in the longer term.

5.2 Professional Development

Exchanges with various national and international collaborators offered SIRC and the programme a rich resource of information, evidence, practice and strategic knowledge. This is a result of historical partnerships with organizations and agencies in the field of SCI and disability. This offered secure and familiar engagements, in particular with Livability, who have played a fundamental role in the development of SIRC including helping to set its strategic direction.

Drawing on the considerable regional and international networks of SIRC and Livability, the programme was able to attract and engage a number of consultants. Of particular significance were the inputs of the consultants engaged in the development of structures and systems in relation to (i) M&E and lesson learning and (ii) nurse training and clinical care development.

It is noteworthy that SIRC also benefitted from the inputs of resource persons at the Asian Spinal Cord Network (ASCoN) and the International Spinal Cord Society (ISCoS). Both organizations were familiar with SIRC and have a strong track record of supporting service and human resource development at SIRC and in Nepal. This enabled resource persons from both organizations to "hit the ground running", work effectively alongside local staff and have a direct and immediate impact.

SIRC's openness to collaborative working and shared learning, which was reciprocal, meant that staff, patients and management recognised the value of national and international knowledge and practice exchanges. This led to innovative and evidence informed practice with operational and strategic decisions being made leading to positive patient outcomes.

5.3 Advocacy and Awareness Raising

SCI peer groups and awareness raising camps were an integral part of the programme's advocacy objective. By focusing on peer-to-peer information sharing, the potential for patients, carers and health staff to be vehicles for knowledge exchange leading to self-driven empowerment was demonstrated. This led to improvements in individual capacities, reduced SCI complications, social interactions and friendship building.

Ongoing education and awareness raising on the management and prevention of SCI complications can contribute positively to the lives of individuals living with injuries. These processes also create valuable social opportunities for peer-to-peer interactions and support where SCI patients and those with other disabilities come together to socialize, share experiences and talk about their lives. This may be one of the few times they can meet others with disabilities given the long distances and difficult journeys that commonly separate communities in the hills.

The programme's structure reflected a holistic life model taking account of different aspects of patients' lives, from physical and mental health to sexual wellbeing and community engagement. Training presentations by peer counsellors/people living with SCIs were part of a deliberate and essential strategy for the success of the approach. Encouraging role models in the form of SIRC peer counsellors helped the programme stress the positives and not the negatives of living with an SCI and the positive actions that can be taken to live full and independent lives.

Monitoring data show that there was a 38% average increase across five knowledge domains selected to reflect the multidimensional nature of living with a SCI. The findings across six districts for the 129 participants of peer group training strongly support the value of peer to peer training and awareness camps in communities which bring people with SCIs and other disabilities together to strengthen understanding of their conditions and offer opportunities for social engagement in an environment likely to promotes positive actions.

5.4 Community Based Activities

SIRC refers its in-patients to partner organizations if they require treatment that cannot be provided by its district rehabilitation points, but without requiring them to travel further than necessary. If SCI patients required basic therapy treatments, they were referred to Handicap International (HI's) district rehabilitation points. Similarly, SCI patients requiring psychological counselling were referred to the Transcultural Psychosocial Organization's (TPO's) district service centres. This component of the work was developed to take advantage of the value added by sharing resources in a collaborative partnership framework out of a common concern for patient rehabilitation needs. *(Please refer to SIRC's separate referral report for details on referrals made to/and by SIRC.)*

During the programme period, referrals were made mutually between SIRC, HI, and TPO in response to needs. This allowed the majority of patients to be treated at district level. This referral system is in its initial stages and will require further energy and commitment to maintain it.

Internal referrals to SIRC through this mechanism led to Community Based Rehabilitation (CBR) teams forwarding patients in response to identified needs and prioritized actions involving clinical interventions and complication management at the center. An examination of patient file summaries, individually and collectively, reaffirmed the deliberate intention to connect a patient's referral reason to his/her rehabilitation plan. In this respect, outcomes centered on the following:

- Bowel Functioning

Bowel regularity was used as an indicator of bowel functioning for SCI patients at SIRC. At admission 35% had regular bowel movements which improved to 72% by discharge. This equates to a 37% increase in regularity among patients and suggests clinical support combined with patient education on bowel management/care effectively improved bowel functioning of these patients.

- Bladder Functioning

Assessment of bladder functioning was recorded at admission based on patients who could either; self-void, a foley is used or clean intermittent self-catheterization (CISC). Based on a comparison of patient bladder functioning records between admission and discharge, a 65% increase in CISC was identified.

- Clinical Outcomes

Comparisons between admission and discharge scores were possible for two of the rehabilitation measures (SCIM and DASS) revealed improvements in patient outcomes by the end of their rehabilitation stay at SIRC.

- SCIM - Functional Independence

A paired ANOVA test was conducted on SCIM scores at admission and discharge. This revealed a statistically significant increase in patient functioning across the dimensions of the measure. This translates into a significant change in SCIM score averages from 50 on admission to 59 on discharge ($p < 0.001$). Individual changes ranged from 0% to 62% and achieved a substantially significant SCIM score improvement.

- DASS - Psychological Assessment

Psychologists at SIRC used the DASS measure containing 14 items related to anxiety and depression. On this basis, a clinical and statistical improvement was calculated between admission and discharge on patients' DASS scores. This showed a 67% increase in numbers of patients identified in grading 0-7 (non case) with no patients categorized as clinical patients by discharge. Borderline cases reduced by 27% by discharge. Statistical analysis of DASS scores showed a significant shift between admission and discharge assessment points ($p<.000$). Together these suggest a substantial impact on psychological wellbeing and adjustment of patients who have been supported by both psychologists and peer counsellors throughout their rehabilitation at SIRC.

5.5 Home Visits

Data generated from 404 SCI individuals living in 14 earthquake affected districts offers a comprehensive evidence base of need against which operational and strategic decisions relating to CBR systems could be based. The larger proportion of patients from the 2015 earthquakes has created a significant change in the responses given by individuals during home visits. There is also a need to factor in the potential impact of various other programme components including equipment supply, vocational training, and peer and caregiver formalized education programmes. The consistent skew of positive outcomes suggests a higher level of reintegration into community life

with greater levels of self-efficacy among patients and their families within the last year. For example, earthquake patients visited by the CBR team between a 3 and 8 month period following discharge, found that 6% currently had a pressure ulcer compared to 15% from the non-earthquake cohort. Similarly, 13% of this group reported having a urinary tract infection (UTI) within the last year compared to 36% of patients who had lived with an SCI for a longer duration.

Considering the challenges experienced by SCI patients when returning to their communities, a focused commitment to improving health outcomes by utilizing formal district level clinical and social support structures, readily accessed through self or agency referral, is needed across the country. It is currently the case that the majority of services are concentrated in Kathmandu, which prevents many PWDs accessing the services they need, even when appropriate referrals are made. It is imperative that structures and systems be developed to bring services closer to the people who need them.

6. TRENDS IN EVIDENCE

A monthly breakdown of key demographic variables was analyzed for the purpose of checking trends within the data across the programme timeline. It was anticipated that this would provide insights for SCI leadership and senior management on strategic, operational and financial planning. Specific attention was paid to patient trends with respect to age, gender, caste, and domicile at the time of injury. A monthly examination of trends revealed that the overall dominant profile of patients was likely to be:

- Male (53%), aged 26-40 (40%), from the Janajati caste (52%) and located in Sindhupalchowk (55%).

Table 5 details the monthly trends across the variables examined in this analysis.

Table 5: Monthly summary trends (showing dominant trend)

Month	Gender	Age	Location	Caste
April (n=4)	Equal male and female	26-40 (50%)	Sindhupalchowk (75%)	Janajati (75%)
May (n=46)	Female (57%)	26-40 (40%)	Sindhupalchowk (40%)	Janajati (48%)
June (n=19)	Male (52%)	26-40 (40%)	Sindhupalchowk (63%)	Janajati (52%)
July (n=7)	Male (75%)	26-40 (40%)	Sindhupalchowk (43%)	Janajati and Chhetri (43% each)
August	No admission	-	-	-
September	No admission	-	-	-
October	No admission	-	-	-
November (n=4)	Male (75%)	All ages equal	Equal distribution across participant locations	Janajati and Chhetri (50% each)
December (n=4)	Male (75%)	41-59 (50%)	Equal distribution across	Janajati (75%)

			participant locations	
January (n=5)	Female (80%)	14-25 (60%)	Equal distribution across participant locations	Janajati (100%)
February (n=6)	Male (67%)	14-25 and 41-59 (33% each)	Equal distribution across participant locations	Chhetri (50%)
March (n=4)	Male (75%)	26-40 (50%)	Kathmandu (50%)	Janajati and Chhetri (50% each)
April (n=6)	Male (83%)	26-40 (67%)	Kathmandu (50%)	Janajati and Chhetri (33% each)
May (n=5)	Male (60%)	26-40 (60%)	Equal distribution across participant locations	Janajati (60%)
June (n=17)	Male (59%)	26-40 (47%)	Sindhupalchowk (29%)	Janajati (59%)
July (n=5)	Male (60%)	14-25 and 26-40 (40% each)	Sindhupalchowk (40%)	Janajati (60%)

These trends were observed during the programme period and suggest a definite pattern among patients being admitted to SIRC with an SCI.

As is visible in the aforementioned table, there were admissions from just after the earthquake until July 2016. For the first few months following the earthquake, patients admitted were those with fresh injuries as a result of the earthquake. Later, from November onwards, patients who had major complications were re-admitted. The major causes for re-admission were falls followed by road traffic accidents.

Because Sindhupalchowk was one of the worst affected districts, SIRC had more patients from there. There were 73 male and 59 female patients. The ratio of male and female patients was proportionate during the first few months after the earthquake but the proportion of male patients increased from November onwards. Proportionally more patients were from the 26 to 40 age group and from the Janajati caste. There were no admissions from August to October 2015 since patients who were freshly injured during the earthquake had already come to SIRC within four months of the earthquake (April to July 2015). However, some ex-patients of SIRC began experiencing complications as a result of the earthquake and were therefore readmitted to SIRC.

Through an analysis of trends, specific needs in the areas of SCI disability and rehabilitation were identified. Although it should be acknowledged that prior service delivery history and evidence gathering directly informed the creation and development of the programme, the opportunity to deliver activities on a much larger and longer-term scale, offered a valuable and instructive opportunity for learning. The responsive manner in which SIRC delivers a MDT model of working,

ensures that services are needs driven. However, access to information, knowledge and experience of SCI treatment and management also increased awareness and understanding of evidence-informed preventative practices to reduce SCI complications. Combing both trajectories of practice, SIRC staff demonstrated their openness and willingness to adapt to identify needs based on the individual circumstance of each patient. This led to a clinical, social, vocational and psychological action plan to improve the lives of each PWD.

7. DISCUSSION OF LESSONS LEARNED

Given the accumulation of information across the programme and taking into account the multi-dimensional nature of programme deliverables, it was deemed necessary to discuss and present lessons learned from within a recognized framework able to inform future planning, strategy and policy for those with SCIs and other disabilities in Nepal. Analytic reflections of evidence generated take account of the specific nature of the emergency context and include the disaggregation of data to pinpoint learning related to targeted actions in response to needs and the subsequent aggregation of information across all planned activities.

A deliberate selection of two specific frameworks was made after considering the knowledge and insights gained from the programme. The first is an overarching, internationally recognized structure that will offer MoH a formal mechanism with which to guide operational and policy planning. The Health Systems Strengthening Framework, advocated by the World Health Organization (WHO) is a strengthening approach that identifies systems building blocks that facilitate access, coverage, quality and safety in order to achieve an improved and equitable healthcare system that responds to patient needs by improving efficiency and reducing financial risks.

The second is GoN's Post Disaster Needs Assessment Framework (PDNA) which draws on the WHO framework described below to structure response and recovery actions in an emergency situation. The 2014 PDNA document states that "When a country is affected by a disaster, the analysis of its effects and the formulation of the needs for recovery and reconstruction are done through a multi-sectoral process, to acknowledge the differences between sectors but also their interdependency. Sectors and their accompanying sub-sectors are defined by the National Accounting Framework of a country. Health as a sector falls under the social sector, together with Education, Housing and Culture. The health sector PDNA process is led by the Ministry of Health (MoH). The Minister of Health needs to designate a Focal Point (FP) to manage the health part of PDNA and recovery process. The MoH recovery FP will work together with the other sectoral FP appointed by the government, which will allow synergies with other sectors relevant to health".

7.1 Health Systems Strengthening Approach

Developing a health systems based programme structure that avoids multiple isolated activities is instrumental in forging pathways of impact across service delivery, policy progression and workforce development. This has been as a result of healthcare financing, leadership/governance and medical technology and was informed directly by information and research. As noted, the overall design of this programme was informed by WHO's Health Systems Strengthening Approach (Figure 2). Multifaceted components reflected in parallel and sequential activities implemented throughout 2015-2016 have demonstrated positive changes in terms of the four goals/outcomes outlined in the WHO approach. Significantly, the vision of SIRC facilitated singular and systemic improvements

across a number of "building blocks" set out in the framework. Deliberately designing the programme to bolster existing support and introduce responses to identified gaps led to a consolidated effect in targeted investment.

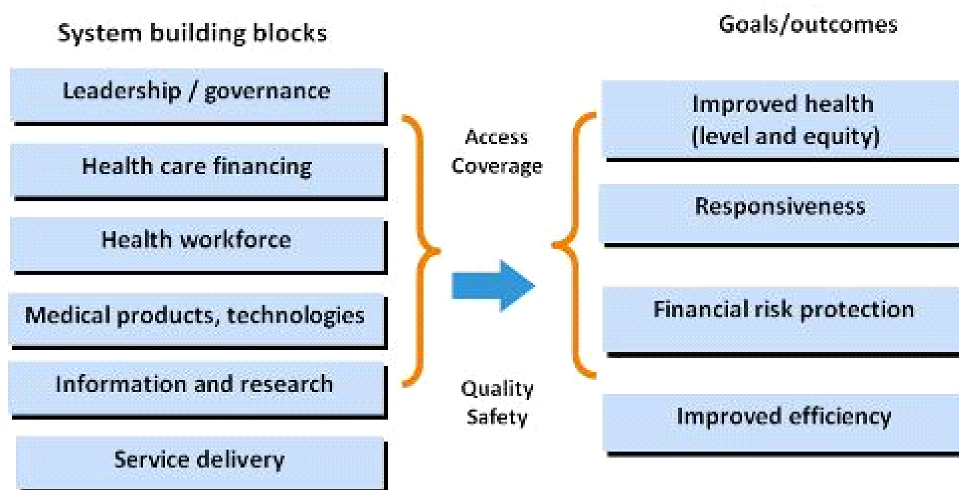

Figure 2: WHO Health Systems Strengthening Framework

Coordination of programme deliverables by WHO Systems Building Blocks

As noted, the overlapping and interconnected activities of the programme were mapped against the WHO health systems framework with its specific building blocks to augment and strengthen services. SIRC designed and implemented responses to needs known to the centre as a result of its service history and engagement with SCI patients. Additionally, information available to SIRC from its network of professionals and practice evidence on arising issues within Nepal proved instrumental in informing the programme's architecture. In this respect, the following activities were developed under their corresponding pillars:

Leadership and Governance

- Support from national and international expertise
- Programme management training
- SIRC and partners integral role and inputs in establishment and successful functioning of injury and rehabilitation sub cluster (IRSC)
- Activities to develop the National Policy and Action Plan on Disability (NPAPD) - Health Component
- Inputs into new National Health Service Strategy (NHSS)

Health Care Financing

- Vocational training packages and seed funding for income commencement for 30 patients
- Funding for rehabilitation packages at SIRC

Health Workforce

- National and District level training to health professionals and practitioners
- Development of Training Manuals and Training Materials

Medical Products and Technologies

- Provision of assistive devices within rehabilitation packages made available through DFID funding

Service Delivery

- Centre based treatment and rehabilitation to 132 patients
- Community based rehabilitation support to 404 ex patients
- Referral system and pathways for 42 ex patients (CBR referrals) to SIRC and 55 referrals to partners such as HI and TPO
- Institutional follow up for 105 ex-patients

7.2 Post Disaster Needs Assessment (PDNA)

SIRC was an active member of the WHO/MoH IRSC Sub Cluster/Thematic Group which considered injury, trauma management, disability and rehabilitation. As a part of the learning from the earthquakes that will inform future preparedness and response strategies, SIRC was commissioned to carry out a review with these key objectives in mind:

- Identify the impact of the earthquake on key population groups, infrastructure and logistics, services and service providers related to the sub-cluster or thematic group to be documented succinctly using available sources of information and processes such as the PDNA
- Establish the critical planning figures estimated to meet the projected demand in terms of types of priority target population groups and services and the intended coverage, based on the impact and assessed needs
- Document the details of interventions that were implemented and services delivered using the following checklists for each specific intervention or service delivered during the three different post-disaster periods.

Thirty five partners across the sub cluster provided detailed and reflective inputs for the exercise. Their feedback was assimilated into resource gaps to be addressed when preparing for disaster or emergency situations. These were set within a quadrant format that categorized resources as follows:

- Human
- Financial
- Materials/ logistics
- Information

Partners drew on the information and experience gained from actions taken during each of the three phases of an emergency timeline: ‘Immediate’ (up to one week post-disaster); ‘Intermediate’ (from one week and up to one month post-disaster); ‘Recovery’ (from one month and up to the end of one

year post-disaster). By doing so a catalogue of "what worked" responses was developed one year after the Nepal earthquakes. These have been ordered under the following timeline phases:

Immediate Phase

- Community participation and social capital of the Nepalese people
- Government support and leadership
- Coordination between GoN, police and army support
- Formation of the IRSC sub cluster for injury, trauma management, disability and rehabilitation
- Existence of a stock pile of devices
- Availability of skilled staff to deliver early rehabilitation including the use of assistive devices
- Work done with health facilities on disaster preparedness and knowledge of administrative staff and WHO procedures for emergency
- Social networks as an effective and immediate communication mechanism
- Technical expertise available from partner organisations
- Willingness of external countries and organisations to provide support
- Experience of organisations in disasters in other countries and in Nepal (floods, 2013)
- Intervention was linked to existing services.

Intermediate Phase

- Access to funds and experience in emergency interventions internationally
- Quality of the network and skills of rehabilitation professionals in Nepal
- Coordination from the MoH through the IRSC with the help of the International Committee of the Red Cross (ICRC)
- Coordination with GoN entities and The Leprosy Mission Nepal's community based groups
- Strong embedding of local partner within the health system
- Rehabilitation outreach effective in identifying needs and providing more timely support to survivors.

Recovery Phase

- Experience of organisations in emergencies internationally
- Availability of funds from existing and new partners/donors
- Availability of skilled professionals in orthopaedic workshops and in general expertise in quality assistive devices services in-country
- Long-term collaboration with local partners and knowledge of the context
- Links with relevant clusters and awareness on needs in mental health among stakeholders

- Good collaborations with local and international organisation for referrals and counter-referrals
- Knowledge of organisations nationally of the local context

Recommendations going forward were described thematically under the following pillars:

- Planning
- Coordination
- Communication
- Logistics
- Human resources.

Cumulatively, the recommendations were ordered according to the “disaster management workflow” diagram which resulted in a set of suggestions laid out by the IRSC sub cluster. These stated:

- To work collaboratively on mapping out every step in the patient’s care pathway as it relates to the disaster response plan
- Identify gaps in the pathways, what these are, where they are and who is responsible for addressing them
- Link organisations to prevent duplication and ensure efficient and comprehensive patient care
- Link to the work of other WHO sub clusters
- Standardise data collected among all organisations and effectively utilise the data for long-term planning
- Ensure data can be aggregated and disaggregated when required to identify date across different levels and types of facilities (e.g., community versus tertiary or primary health facility).

<u>Health sector assessment and analysis framework</u>

Health sector analyses are based on the health system framework using the six WHO building blocks. The health system strengthening framework is used in an assessment and analysis matrix that guides the health recovery team to establish the baseline, a systematic assessment of changes in the epidemiology of the burden of disease, the performance of the main health programmes and the six health system building blocks. It takes into consideration the assets, stakeholders, and processes that are typically included in the sector and how they may be affected by a disaster. This enables analysis of how pre-existing performance and constraints may affect the recovery needs to restore access to essential services, meet new health needs and identify priorities for ‘Building Back Better’. Using the health systems strengthening framework allows the linking of recovery planning with the longer term national health development plans. Figure 3 provides a summary of the link between the two frameworks and projected outcomes of the interaction between them.

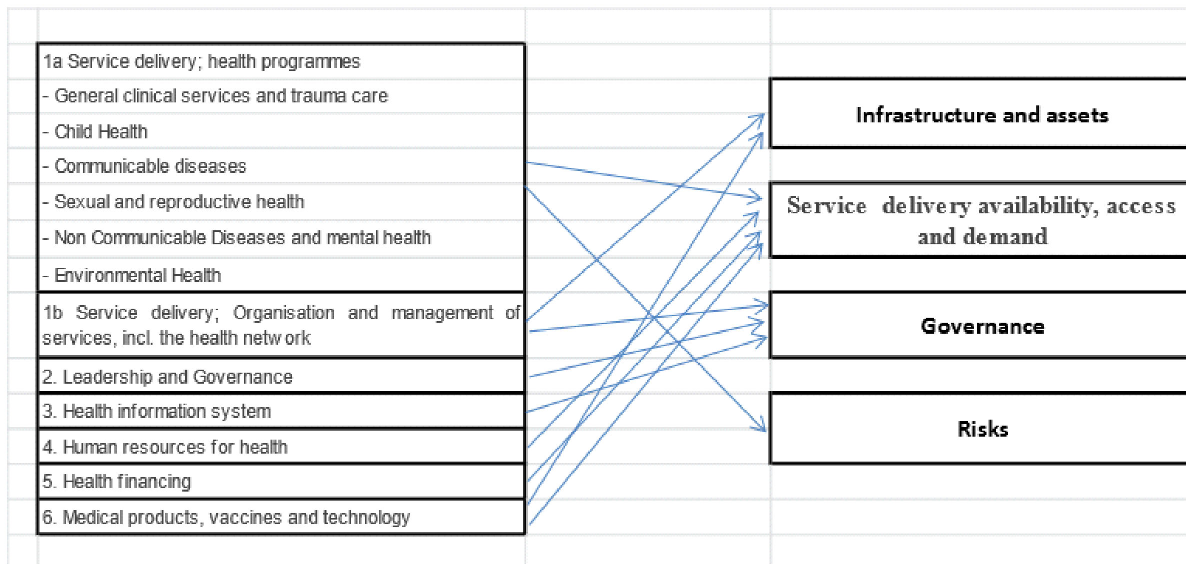

Figure 3: Link of the health system framework with four PDNA recovery elements

Using the analytical matrix based on health sector response domains and building blocks, SIRC activities undertaken in the DFID programme can speak to the relevance and importance of their actions in a pre- and post-disaster environment. The remit of SIRC sits under "Service Delivery 2: Health sector response for injuries". In terms of early recovery actions for the rehabilitation of disabled persons, it was suggested that these include:

- Rehabilitation of persons with disabilities
- Strengthening of the capacity for prostheses and rehabilitation
- Disability care to be taken into consideration in new health system

Under the Health Workforce pillar it was recommended that the following should take place in terms of "early recovery response" actions:

- Replacing, strengthening and reactivating the workforce
- Reconstruction and reopening of training facilities
- Adapt training programmes to new relevant issues
- Task shifting capacity building in first aid, disaster preparedness, and response and recovery

8. PROGRAMME DRIVING FORCES

A health system consists of all the organisations, people and actions whose primary interest is to promote, restore or maintain health. The implementation of this programme is seen as an example of how a micro level system, can be informed by and influence a larger macro system through district level provisions and policy development. The main features across all activities and planned deliverables were:

- Responsive actions to identified needs
- Evidence informed practices and activities

- Expertise in clinical, financial, management, and strategic fields for SCI treatment, management and rehabilitation
- Diligent oversight and leadership
- National and international networks of professionals and practitioners in SCI.

9. PROGRAMME RESTRAINING FORCES

Through a reflective learning approach, it is important to identify the enablers of a programme and take account of factors impeding outcomes. By doing so, future planning can try to mitigate these and potentially improve on the evidenced impact of actions documented to date. As a result of a comprehensive review of the professional practices, the following restraining variables have been identified:

- Influence of external events (fuel shortage, September 2015- February 2016)
- Disconnected systems outside SIRC impeding deliverables and outcomes
- Competing priorities in the strategic context of programme objectives
- Spatial disparity in availability of comprehensive rehabilitation supports for SCI patients at the district level

10. CONTINUTION AND SUSTAINABILITY OF PROGRAMME ACTIVITIES

10.1 Referral Systems

Continued employment of CBR workers will allow SIRC to continue to identify those with SCIs having physical and psychological complications and to refer them appropriately. It will thereby enable the organization to continue to develop the referral process with increasing numbers of partners and institutions.

10.2 Care and Rehabilitation Systems

The programme supported the overall strengthening of clinical and rehabilitation services and systems at SIRC. Internal systems including documentation, standardization of care, goal planning, and patient and caretaker education have all been enhanced. These positive developments will be maintained and this will help ensure that newly admitted patients in the future will continue to benefit from this programme.

10.3 Policy Development

"10 year action plan on disability prevention and rehabilitation of Nepal"

In the aftermath of the earthquake, the early recognition of SIRC as the central focal and referral point for SCI helped ensure that patients with SCIs were referred to the organization.

This recognition, in turn, enabled SIRC to attain funds from a range of donor agencies such as DFID to support a rapid increase in patient numbers.

SIRC's positive and proactive response and its involvement in post-earthquake coordination and planning mechanisms within MoH also showed that SIRC played a leading role in the development of immediate and intermediate plans within the injury and rehabilitation sector. These engagements led directly to SIRC's significant involvement in the process to develop a ten year action plan on disability prevention and rehabilitation in Nepal.

Because disabled people are entitled to the same human rights as other citizens, as confirmed by Nepal's constitution, concerning disability rights, equality will be promoted in the health and rehabilitation sector and also within other services and facilities to create equal opportunities.

To achieve the abovementioned aims, the health and rehabilitation services promised by the GoN in the UN convention and the duties formulated in the process should be completed swiftly without bias towards disabled people. This action plan has also created a list of those duties.

SIRC has fully reflected on how they can provide meaningful, evidence informed and sustainable responses to the key concerns raised in the ten year action plan. Particular emphasis was placed on how SIRC as a centre for SCI and neurological rehabilitation can actively address the recommendations set out in the policy document. SIRC has operational, clinical and strategic experience and expertise which offers MoH access to a valuable resource developed internally in Nepal. The additional input from international networks of professional bodies in the area of disability, SCIs and rehabilitation created opportunities for global perspectives and learning that is contextualized and managed by a Nepalese NGO. Specifically this will enable SIRC and its formalized network of partners and collaborators to contribute to actionable responses to policy driven recommendations such as:

- Prevention
- Rehabilitation
- Human Resource Development
- Service development and delivery

Recommendations put forward from the policy document are directly informed by an analysis of information gathered across stakeholder groups. These were categorized according to the area of identified priority for PWD in Nepal and included challenges around promotional health services, medicine/treatments, prevention, rehabilitation, human resources, information and statistics, and attitudinal and physical barriers. Reflecting on these in relation to the strategic and operational goals of SIRC, and the recent completion of the DFID programme activities, a number of significant overlaps have been noted.

Promotional health services: It was reported in the national policy document[3] that, "programs on promotional health services targeted to the PWDs are non-existent" and, "there is the lack of promotional programmes on reproductive health services targeted to PWDs".

Prevention: This refers to how injuries that lead to disabilities are acquired such as industrial accidents, road traffic accidents (RTAs) and falls. However, despite knowledge about the

[3] MoHP National Policy on Disability

considerable risks involved, efforts to prevent injuries are not widely promoted nor measures taken to prevent accidents.

Service delivery, management, and prevention: "Due to geographical remoteness, low economy, and lack of awareness in families, people with disabilities rarely go for check-ups at health institutions. There are numerous cases where disabled people are deprived of medication facilities due to poverty. The vicious circle of disability and poverty has aggravated families continuously"[4]. In addition, the provision of free health checks where available tend not to be utilized by PWD. This is reflected in essential medicines for disability health matters not being available on the "free drugs list". The research further identified that "individuals with spinal cord injury are compelled to lead a painful life as they are not in a good economic condition to go for treatment".

Many hospitals do not have operating disability rehabilitation programmes. Therefore, patients are dependent on donors who they expect to assume responsibility for them throughout their lives. There are not enough rehabilitation centres to meet the demand. There is a lack of qualified workers in rehabilitation services, there is no standardization of service, and authentic, qualitative resources and services are also lacking. It is suggested that such programmes should be run with a professional approach i.e. using professional providers.

Rehabilitation: "In the community, even if the people with disabilities are identified, they are not referred to the centre of excellence. This leads to greater problems as people with disabilities will be deprived of the treatment they need and their conditions will worsen. This area is weak in part because the aim of the National Childhood Disability Management Strategy under MoH's Child Health Division was not followed to manage the separate unit".

Psychosocial Counselling Services: These are not accessible for people with accident related disabilities in various districts. It was suggested by the action plan research, that due to the high rates of psychosocial disability among the victims, this is an issue that needs to be addressed. Participants in the research suggested that there is a deliberate focus on physical health issues with less emphasis placed on a "holistic rehabilitation facility for psychosocial disability with national and international organizations working for psychosocial disability" and so such treatment is lacking at grass roots level. A specific recommendation within the document is that, "psychosocial counselling should be bound by the law of the country and there should be one regulatory body for such professionals to regulate them".

Medical technology: There is a lack of a reliable mechanism for obtaining assistive devices and such devices often are of low quality. As a result, people with disabilities often refuse to use assistive devices and there is a high dropout rate in their use. This has been coupled with a lack of trained and proficient staff in assistive technologies and the provision of repairs at designated and recognized centres.

[4] Summary of Ten year Strategic Action Plan on Prevention and Rehabilitation of Disability in Nepal

11. LESSONS LEARNED

11.1 Health Systems

By understanding what is needed to strengthen a system that can appropriately respond to SCI patients in order to manage health issues and prevent further complications associated with the injury, structures were developed that included skilled and competent professionals working within a MDT approach reflecting evidence based practice. In the case of SIRC, it is an example of a health workforce that is framed and supported by strategic and operational leadership under the guidance of an effective governance structure. The delivery of a complex and multilevel programme having parallel operational strands has been made possible by ensuring a transparent approach to due diligence processes that places accountability at the forefront of its responsibilities.

11.2 Vocational Training

The geographical location of trainees is taken into consideration when offering patients at SIRC a particular vocational pathway that is most likely to offer a realistic route to income generation. Business skills including marketing and financial management are taught in combination with practical skills in sectors that are relevant to the communities to which patients will return. In preparation for income generation, apprenticeships or internships should be a formalized part of the training programme to build the confidence and experience of trainees through practice hours in an established workplace.

11.3 Community Based Rehabilitation

Through DFID, SIRC was able to upscale its community outreach programme rapidly. This resulted in achievements such as 404 follow up visits conducted and the collection of extremely valuable information on the successes and challenges people with SCI encounter post-discharge. It also allowed for a rapid increase in referrals using the system developed in the programme. While there is naturally a need to take appropriate actions in the response phase of an emergency, it is essential to plan and prepare resources and a longer term strategy that takes account of the recovery and rehabilitation phases of an emergency situation. Community based rehabilitation strategies should be a formal and integrated part of preparedness and response to reflect the lifelong management issues faced by SCI individuals as they return to their communities and embark on a phase of assimilation with their injury. *(Please refer to separate CBR reports of SIRC for details on data and further information.)*

11.4 Referral System

One of the specific sustainable actions implemented by SIRC as a partner in the referral partnership was the communication between SIRC and district hospitals in order to share details of referral pathways for SCI patients who access their services. The sharing of information concerning referral documents, referral pathway criteria, and details concerning rehabilitation supports offered at SIRC between staff from district hospitals and SIRC will contribute significantly to increased access to healthcare for SCI patients at district level. *(Please refer to separate referral reports of SIRC for detailed information on referrals.)*

11.5 Partnership Working

SIRC, HI, and other organizations have been actively involved in the process of establishing a health component and action plan as part of the NPAPD. It is anticipated that this action plan will include activities related to increasing the quality and coverage of rehabilitation services beyond the Kathmandu Valley. This will provide further opportunities to utilize and enhance the referral processes and systems developed through this programme.

12. RECOMMENDATIONS AND "WHAT NEXT?"

12.1 Context

The post-disaster context has illustrated the urgent need to focus on neglected areas of mental health, rehabilitation and disability. There is a greater realization and awareness that those injured and traumatized in the earthquake alongside many other disabled people in the country will require long term rehabilitation, follow-up and health maintenance support if they are to survive and remain as active participants in society.

The DFID annual programme review 2016 reported that its support to restore health services in the 14 most affected earthquake districts is delivering effective and much needed interventions. The programme represents good value for money, particularly as it focuses on access to essential health care services and on areas of unmet need for spinal injury, rehabilitation and psychosocial care in a post-disaster context".

Through heightened awareness, service and system developments, and improved collaboration and coordination between government and organizations operating in the rehabilitation sector, there is now a golden opportunity to establish a systematic rehabilitation programme across Nepal. The introduction of federalism and probable decentralization of health service delivery brings with it opportunities to increase the quality and coverage of health and rehabilitation services beyond Kathmandu to parts of the country where services are limited or non-existent.

The following section outlines the problems faced currently and suggests ways forward.

12.2 The Problem

The World Report on Disability by WHO highlights that 15% of the world's population has a disability and 80% of these people live in developing countries. They experience poorer health outcomes and face widespread barriers to accessing services for healthcare, rehabilitation, education, employment, and social services etc. Barriers include inadequate legislation, policies and strategies, a lack of service provision, negative attitudes, discrimination, and inadequate funding. WHO also highlights that half of all disabled people cannot afford necessary healthcare and are 50% more likely to suffer from catastrophic health expenditure.

In Nepal, the availability of appropriate injury, rehabilitation and community inclusion services, particularly beyond the Kathmandu Valley, remains extremely limited resulting in high levels of morbidity and mortality for people with disabilities. Many of these people are poor and do not have the means to travel and access treatment and rehabilitation services in Kathmandu. Due to the

unavailability of services, many suffer needlessly, die prematurely and leave behind impoverished families.

The recent work carried out to develop an action plan to support the implementation of the National Policy and Action Plan on Disability - Health Component, highlighted that, "due to geographical remoteness, low economy and a lack of awareness in the family, people with disabilities rarely go for medical check-ups or treatment at health institutions, leading to failed diagnosis, long term complications, and high levels of mortality". It emphasized that, outside Kathmandu, rehabilitation services are not available and there is a lack of qualified and trained staff in rehabilitation services as well as no standardization of service.

This report provided key recommendations:

- There is a need for strong coordination and collaboration mechanisms among ministries, national and international organizations, service providers and organizations providing financial and technical support

- Government, non-government, and private sector organizations should develop public-private partnerships which are seen as a cost effective method to reach disabled people, so far as they are not yet reached by existing services

- At least one fully equipped disability and rehabilitation centre with training manpower in each province or region should be created

- The launching of national level information, education, and communication programmes to increase awareness about and actions concerning disability and rehabilitation issues should be carried out.

Many of the barriers mentioned above are avoidable and manageable if the appropriate support and services are provided. Through this DFID supported programme, SIRC and other partners have highlighted that even in the post disaster scenario, people with serious, complex and disabling conditions such as SCIs can go on to live productive and dignified lives post-injury if appropriate services are provided.

It is also the case that the new National Health Service Strategy (NHSS) recognizes the urgent need to improve injury and rehabilitation services for people with disabilities at national level. Within the NHSS Basic Health Care Package, rehabilitation is now included in the "basket" of essential service. As requested by the Implementation Body of the NHSS, The Leprosy Control Division/MoH, along with inputs from SIRC and other organizations in the sector, recently provided detailed recommendations on how the quality and coverage of services for people with disabilities could be increased at a national level.

In line with the principles and intended outcomes of the NHSS, WHO and the Global Disability Action Plan 2014 – 2021, the proposed strategy submitted to the NHSS Implementation Body was three fold:

- To improve access to health services and programmes

- To strengthen and extend rehabilitation, support services, and community based rehabilitation

- To strengthen the collection of internationally comparable data on disability and support research on disability and related services

12.3 SIRC's Role Going Forward

From humble beginnings in 2002, SIRC has evolved into a National Level Rehabilitation Centre with 100 plus beds. In the face of enormous pressure and with support from DFID and others it rose to the challenge and provided over 140 earthquake survivors with lifesaving and essential services. We believe that we, with support from our regional and international partners, have a big role to play in the national development of services for people with SCI and other disabilities.

We realize however that we cannot, and should not, try to do this alone. We realize that, for vital services to be sustainable, they should be provided through government institutions and/ or through public private partnerships.

Taking figures outlined by WHO in the World Report on Disability, approximately 15% or 3.3 million people in Nepal have a disability. Many of these people will require healthcare and rehabilitation services if they are to maintain health, functioning and live inclusive lives in their communities. Most will not have access to the services they need and a major drive is required to ensure Health Systems are strengthened so that they become inclusive to the needs of people with disabilities.

SIRC is committed to making a positive and significant contribution to the implementation of the NHSS in relation to the establishment and delivery of healthcare and rehabilitation services for people with disabilities. We will also support the implementation of the Third Nepal Health Sector Programme (NHSP 3) and will contribute to the attainment of its aim to improve health outcomes for the poor and vulnerable in Nepal through the four core areas: leaving no one behind, better evidence based planning, budgeting, and stewardship of service, improved quality of care, and earthquake restoration and disaster preparedness.

12.4 Health System Strengthening

SIRC has developed a new and ambitious five year strategic plan (2016 - 2020). Central to this is the continued strengthening of services at SIRC. Alongside this, SIRC is committed to sharing its experiences and expertise and to working in partnership with government and other organizations to strengthen and increase the quality and coverage of rehabilitation services across Nepal. Many people with disabilities remain poor and vulnerable with little access to services and opportunities. We are determined to challenge and change this situation.

As a framework, we will continue to adopt the WHO promoted "systems strengthening" approach. This approach aims to improve the performance and functioning of health systems with consideration of six building blocks: leadership and governance, service delivery, human resources, health technologies, information systems, and financing. It is the interaction of these components as well as coordination across other sectors such as education, employment and social welfare that enables people with disabilities to access the care they need.

1: Leadership and governance *involves ensuring strategic policy frameworks exist and are combined with effective oversight, coalition-building, the provision of appropriate regulations and incentives, attention to system-design, and accountability*. Areas of priority and focus will include working collaboratively and strategically with the GoN to support:

SIRC's engagement with the GoN and other organizations in relation to the development of national policy, strategy and action plans has increased substantially during the programme period. The past year has laid a strong foundation on which to build in the coming years. Strong and progressive policies and action plans in relation to the development of injury and rehabilitation services can help fast track the development of essential injury and rehabilitation services across Nepal.

Areas of priority and focus will include:

- Finalization of the ten year action plan on prevention and rehabilitation of disability in Nepal
- Linkage and synergy of the ten year action plan to the implementation framework of NHSS and NHSP 3
- The formulation of guidelines for the design, establishment and standardized operation and management of national, provincial, and district level rehabilitation centres and facilities.

2: Service Delivery: *Good health services are those which deliver effective, safe, quality personal and non-personal health interventions to those who need them, when and where needed, with a minimum waste of resources.*

The programme has clearly demonstrated the impact of in-patient services and outcomes achieved by people with SCIs. During the programme timeframe, SIRC was able to establish a programme that allowed for the readmission of patients for follow-up complication management, and top-up rehabilitation. A step-down facility has also been developed. These services continue and will need to be further developed. SIRC has also established a partnership with a Korean organization that will support the upgrading of vocational assessment and training services at SIRC.

Community based rehabilitation: The findings relating to the 404 individuals who received home visits through the programme, call for a series of actions that should be initiated, maintained, or strengthened to improve the active rehabilitation and integration of SCI individuals following discharge from SIRC. This suggests that CBR activities cannot focus solely on addressing clinical outcomes through medical intervention but must embed the components of the WHO matrix that identifies health, education, livelihood, social and empowerment as the driving components around which CBR activities should be based. The findings of these reports mirror the dimensions of this matrix and affirm the multiple dimensions of rehabilitation around which all planning and response should be based.

Areas of priority and focus for SIRC include:

- Continued strengthening of SCI and neuro-rehabilitation services at SIRC
- Strengthening SIRC's community outreach and rehabilitation services

- Promotion and proactive support to establish services beyond Kathmandu. In particular, working with Government to establish a model Provincial Rehabilitation Programme. Core to this will be the creation of a Provincial Rehabilitation Centre. This, in turn, will become a hub to support the development of: smaller district rehabilitation units; outreach services; follow up and community integration programmes; province-wide human resource development programmes for healthcare workers; wheelchair and assistive device assessments, fitting and distribution services; information, advice and a resource centre; province-wide awareness programmes on disability and rehabilitation; province-wide information system development and research programmes related to disability, rehabilitation and inclusion.

3. Human Resources: *A well-performing health workforce is one which works in ways that are responsive, fair and efficient to achieve the best health outcomes possible, given available resources and circumstances, i.e. there are sufficient numbers and mix of staff, fairly distributed; they are competent, responsive and productive.*

- Provincial and District level training from SIRC should be expanded to all regions of Nepal based on demonstrated improvements in knowledge, skills and confidence of health practitioners in SCI management and rehabilitation. Offering district level training that increases capacity at this level to understand how to manage a SCI from the point of admission to rehabilitation, will actively contribute to reducing the risk of additional complications and mitigate increases in injury severity through proper handling and clinical interventions. SIRC has a strong track record of working with government and the National Health Training Centre (NHTC) in training delivery. The organization is well placed to support many more people to increase skills, knowledge and confidence in the management of people with rehabilitation needs.

Areas of priority and focus will include:

- Development of SIRC training programmes and training facility

- In collaboration with MoH, NHTC and other organizations supporting the design and establishment of a National Injury and Rehabilitation Training Programme

- Supporting the establishment of a new and innovative rehabilitation training course, in particular for mid-level health workers

4. Information Systems: *A well-functioning health information system is one that ensures the production, analysis, dissemination, and use of reliable and timely information on health determinants, health systems performance and health status.*

- The formal structures of a robust and comprehensive data gathering system established during the DFID programme should continue to strengthen and evolve to ensure SIRC maintains a focus on demonstrating patient outcomes through evidence informed practice. All staff should be regularly informed of revisions and additions made to the system and have the opportunity to reflect on how information gathered on treatment activities with patients is influencing the care pathway and outcomes of SCI patients.

Areas of priority and focus will include:

- Continued strengthening of standardized documentation, data gathering, and outcome measurement systems
- In collaboration with ASCoN and ISCoS, supporting the development of standardized data collection systems to determine causes of SCIs in Nepal
- Development of research capacity and research programmes within SIRC
- Working with government and other organizations to develop collaborative and multi centre research programmes
- Development of mechanisms to effectively utilize data , information, and research to inform policy, programme, and practice development

5. Health Technologies: *A well-functioning health system ensures equitable access to essential medical products, vaccines, and technologies of assured quality, safety, efficacy, and cost-effectiveness, and their scientifically sound and cost-effective use.*

- SIRC over the past year with support from DFID and other partners has been able to supply wheelchairs and assistive technology to most of the patients that it admitted. This said, it remains a major challenge for those with SCIs and other disabilities to access affordable and appropriate assistive technology.

Areas of priority and focus will include:

- Continued strengthening of assistive technology and diagnostic services at SIRC
- Working with partners to increase access to appropriate and affordable wheelchairs and assistive technology nationally
- Development of a training programme for health technologists

6. Health Financing: *A good health financing system raises adequate funds for health in ways that ensure people can use needed services and are protected from financial catastrophe or impoverishment associated with having to pay for them.*

- SIRC in the month following the earthquake developed a comprehensive mechanism to cost "packages" of rehabilitation for people with SCIs. This in turn allowed SIRC to set targets and generate funds for the delivery of these rehabilitation packages. Of particular note was the contribution made by DFID in supporting rehabilitation packages for 130 patient and follow up/readmission packages for 100 patients.
- The case remains, however, that the majority of patients presenting for rehabilitation at SIRC are poor and in many cases have exhausted their funds by the time they reach the centre. This scenario puts constant pressure on SIRC to raise funds to provide services for this group of people. The relationship built with the GoN over the past year and the

recognition of the quality and impact of SIRC's work and rehabilitation programme has now laid the ground for ongoing discussions with Government on a funding support mechanism for the care and rehabilitation of people with SCIs. This has the potential to develop into a framework that may enable poor people to access the care they need in other institutions and organizations.

Areas of priority and focus will include:

- Working with MoH to establish mechanisms to cost and fund rehabilitation packages for poor and vulnerable people
- Raising funds to sustain and continue to develop rehabilitation services at SIRC
- Contributing to the realization of funds to support rehabilitation service development in other parts of Nepal.